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ABSTRACT

The paper, containing 80 statements, addresses the roles and needs of parents regarding their handicapped adolescents' education. Following an introduction is a chapter on the importance of basic attitudes and the danger of some negative parental attitudes. Service needs, covered in a third chapter, are seen to include provision of information, residential and support services, and financial help. Chapter IV looks at obstacles to parent-professional collaboration and offers suggestions for increasing collaboration. The needs and rights of handicapped adolescents is the topic of chapter V. Among conclusions in a final chapter is that parents should be fully involved in the process of assessment and strengths and should be seen as full members of the multidisciplinary team. (SB)

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THE EDUCATION OF THE HANDICAPPED ADOLESCENT

Roles and Needs of Parents of Handicapped Adolescents

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THE EDUCATION OF THE HANDICAPPED ADOLESCENT

Roles and Needs of Parents of Handicapped Adolescents

1. The attached paper has been prepared by Peter Mittler, Sally Cheseldine and Helen McConachie of the Hester Adrian Research Centre, University of Manchester, United Kingdom as a contribution to the CERI project "The Education of the Handicapped Adolescent".

2. The views expressed are those of the authors and do not commit either the Organisation or the national authorities concerned.

SUMMARY

The parents of handicapped adolescents have specific problems and needs given that their children as they grow older do not necessarily gain independence and leave home. This paper outlines some of the contours of the family situation of parents caught between the necessity of continuing care of their child and the desire to encourage as much autonomy as possible. Given that "the main role of parents of handicapped adolescents is fundamentally the same as that of parents of any other adolescent - to provide a loving and secure home and to prepare them to live independently in the community ", the authors ask the question of what facilities can enable parents to carry out their role.

Before outlining the specific needs of parents, the authors point out the importance of basic attitudes and the danger of some "negative parental attitudes" in the face of change in the child. The recommendations made are first of all based on the service needs of parents: the need for information, for residential and support services and for financial help. The partnership between parents and professionals from the beginning is seen as the hallmark of a good service for handicapped children. Different modes of collaboration are outlined, and the various obstacles and ways of overcoming them are pointed out.

The final chapter concerns itself with the needs and rights of handicapped adolescents. Basing their arguments on the United Nations Declaration of Rights of Disabled Persons (1975) the authors state that: (1) handicapped adolescents have the same civil and political rights as other human beings; (2) the right to help to become as self-reliant as possible; (3) the right to proper medical care and treatment; (4) to education, training and rehabilitation and guidance; (5) a decent level of living, including the right, according to individual abilities to secure and retain employment; (6) a normal living environment within a family where possible, including participation in all social, creative or recreational activities; (7) protection from exploitation, discrimination, abuse or degrading treatment.

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ROLES AND NEEDS OF PARENTS OF HANDICAPPED ADOLESCENTS

I. Introduction

1. Three main phases can be detected in the relationship of professionals and parents of handicapped children. For many years parents received little or no help from professionals and were largely left unsupported. Such advice as they received tended to be negative and rarely included practical suggestions on what they could do to help their child at home. Indeed, parents were at one time frequently advised to place the child in residential care. The second phase, beginning towards the end of the 1960s, took the form of training parents to use some of the techniques previously restricted to professionals and regarding them as "co-therapists". Many parents were quick to learn these techniques and put them to good use with their children; research workers began to investigate the most effective methods of training parents and enlisting their help in carrying out programmes devised by professionals (O'Dell, 1974; Cunningham, 1975). But although parents and children may have benefited from such programmes, professionals have largely worked on the assumption that they know best what the child should learn and therefore what the parents should do at home. It is not surprising that some parents have felt that such a one-way approach did not meet their needs and resented the implicit assumption that professionals knew what was best for their child. Furthermore, parents have not always been able to meet the demands of the programmes being devised by professionals; it has been suggested that "some professionals have been so busy teaching parents to be teachers that there may not be enough time left for parents to be parents" (Mittler, 1979). Such a "transplant" model is likely to be rejected (Jeffree, 1980).

2. We are now entering a third phase in which attempts are being made to develop a partnership on a basis of equality. Both sides contribute their own areas of knowledge and skill but parents are encouraged to retain their sense of identity as parents and to remain true to their own natural style of relating to their child. The approach starts with the needs of the child in a family context and tries to mobilise the existing resources of the family. Individual members of the family may acquire specific skills and techniques as a means to an end but the emphasis lies on the individual family setting about the task in its own way and in its own style. Although the approach is somewhat more relaxed, a more prescriptive model may be appropriate to meet particular needs.

3. Parents of handicapped adolescents have had very little help in the past and may well have become accustomed to their isolation from professionals. By the time their child is ready to leave school, some parents have come to accept a role as permanent caretakers, just as some adolescents have largely accepted a role of passivity. Parents of adolescents and young adults have often reached a modus vivendi and a quality of

adjustment to their situation which needs to be respected and which is in any case not easily changed. Many families are resistant to procedures and programmes which emphasize their difference from other families, e.g. visits from professionals, membership of societies, the arrival of special transport at their door. "In our attempts to 'normalise' adolescents, we run the risk of 'denormalising' the family" (Jeffree, 1980).

4. The period of school leaving marks a critical point in the life of the family as well as that of the adolescent. But although there is now a considerable literature about parents of younger handicapped children, very little is known about families of handicapped adolescents and young adults. How far do such families have special and distinctive needs? To what extent do the roles of parents of handicapped adolescents differ from the role of parents of younger children, both those who are handicapped and those who are not? What kind of services do families need to help them to fulfil their role?

> Our working assumption is that the main role of parents of handicapped adolescents is fundamentally the same as that of parents of any other adolescent - to provide a loving and secure home and to prepare them to live independently in the community.

5. Ordinary families carry out this role in a variety of ways; some do so explicitly and overtly, others more implicitly or by providing models which they hope the young person will follow. We have relatively little information on how families normally perceive their role or carry out their task of preparing for independent living. We do know that they can draw on the experience of their friends and family and that the final outcome is one in which their son or daughter becomes independent and leaves the parental home.

6. But this is not generally the outcome if the child is severely handicapped. Such families may expect to have to continue to provide a home indefinitely or until circumstances make it impossible for them to continue to do so. Clearly each family will differ in its expectations of the handicapped adolescent and in particular of the extent to which he or she can live independently in the community. These expectations may not necessarily coincide with those of professional staff involved.

II. Families' Needs and Attitudes

7. It is all too easy to generalise about "the needs of families" and to overlook the enormous range of individual differences. These will differ as much as, if not more than, the needs of any other families. We should also beware of drawing too sharp a distinction between parents of handicapped and non-handicapped people. For example, in studying the families of cerebral palsied children, Hewett (1970) concluded that "families meet the day-to-day problems that handicap

creates with patterns of behaviour that in many respects deviate little from the norms derived from studying the families of normal children. They have more similarities with ordinary families than differences from them" (p. 194). Most families of handicapped people have also had several other normal children; the mentally handicapped child is often the last born in the family (46 per cent in both Moncrieff, 1966 and Cheseldine and Jeffree, 1980). Thus many parents will have considerable experience not only of childrearing, but also of helping their older children to achieve independence.

8. To stress the essential normality of the families is not to deny the range and severity of the problems they face; rather it is to counter the assumptions and stereotypes which have so often been used by professionals and researchers about the underlying social pathologies to be found in the families. Kew (1975) called them "handicapped families". The danger lies in the consequent lack of appropriate action by professionals in response to families' needs. For example, parents seeking help at an early stage report being labelled "overanxious" and denied credit for close observation of their child (e.g. Schaefer, 1979). Families seeking residential care for their handicapped member may be investigated for "guilt" and "rejection"; those not seeking relief may be labelled "over-protective". The behaviour of the families may be interpreted as abnormal whatever they do (Wilkin, 1979). It is interesting to note in this context the explanation suggested by Fox, 1974 for his questionnaire finding of increased levels of "hysteria" in parents of handicapped children: "A facility for brashness, over-dramatisation, and a refusal to be intimidated by authority or status, have become necessary for obtaining the best from our services."

9. The brothers and sisters of handicapped people have also been portrayed as a group very much at risk emotionally, and institutionalisation was (and may still be) recommended "for the sake of the normal children". McMichael (1971) and Kew (1975) suggested that up to a quarter of siblings had moderate to severe problems in adjusting to the situation of handicap. However, these and similar studies were conducted on families who were already receiving help from professional agencies. The few researchers who have talked to the siblings themselves reflect a picture of generally good adjustment by siblings, who mention positive aspects as well as drawbacks (e.g. Grossman, 1972; Grailiker et al., 1962). Extra burdens tend to be reported particularly for older sisters, who may be expected to share the increased daily tasks of caring for the handicapped child (Farber, 1959; Fowle, 1968; Gath, 1974; Wilkin, 1979).

10. The main tradition of British research on the families of handicapped people has been to look pragmatically at daily living problems. Most studies have considered the families of school age children or younger - a notable exception being Bayley (1973) who interviewed the families of severely handicapped adults living at home. Interview studies in general have had two major drawbacks: the lack of comparative

information on families of non-handicapped adolescents and the lack of objective data, for example, through over-dependence on information from parents. However, a number of observations relevant to the families of handicapped young people may be made.

11. Older studies painted a graphic picture of the financial and housing needs of families. Tizard and Grad (1961) found that 40 per cent of their London sample whose "severely subnormal child" (aged up to 45 years) lived at home were overcrowded by local standards. Both low income level and overcrowding were somewhat relieved in the comparable sample whose children had been institutionalised. A follow-up of the same families whose handicapped member lived at home found improved housing standards, but greater financial hardship, through more parents being retired or infirm (Moncrieff, 1966). In a more recent study in an urban area, Wilkin (1979) noted that 10 per cent of families he interviewed still had no inside toilet. So the basic housing needs of families caring for a severely handicapped person can still not be said to have been met completely in Britain. Of families interviewed by Lonsdale (1978), 71 per cent felt their financial circumstances were adequate, but added that unless they had the weekly Attendance Allowance and grants from the Joseph Rowntree Trust many more would be struggling. Poor housing and financial hardship have a consequent bad effect on health, which in turn will be aggravated by the care of a handicapped child (Carnegie United Kingdom Trust, 1964). As the handicapped person grows older, parents' health is likely to become poorer.

12. Problems of definition affect much of what is said and written about parents' attitudes, felt needs, and reports of their child's behaviour. For example, what types of "behaviour problems" make the difference between a family being able to keep their handicapped member at home, and having to seek an alternative? One study of teachers reported that the most frequent type of behaviour problem was "non-compliance", but that the most difficult to manage was stereotypic behaviour (Wehman and McLaughlin, 1979). Both types of behaviour may cause embarrassment in public, but the latter may restrict a handicapped young person's possibilities for independent activity more than the former. Even in the older studies of families, management of the behaviour of the handicapped person is cited as the greatest problem (and the one most likely to lead to application for institutionalisation) (Tizard and Grad, 1961; Holt, 1958; Bayley, 1973). In our study of mentally handicapped school leavers, 41 per cent of parents mentioned behaviour problems with regard to the young person's leisure time (Chaseldine and Jeffree, 1980). Bayley (1973) estimated that 18 per cent of severely subnormal adults living at home could not be left unsupervised for even an hour.

13. Several studies which have followed up handicapped young people some years after leaving school strongly suggest that many of them are not only without services but largely isolated from the community resources available to other young people. Even those that can attend some form of day care often lead

lonely and unstimulating lives, and have very limited opportunities to make and meet friends or to take part in leisure or recreational activities. Many do not even have access to any form of day care or further training or education; consequently they are forced to spend most of their time at home and are thrown back on their own resources (Segal, 1971).

14. On the other hand, we should also note that some of the school leavers in our survey do not present any problems; for example, only 6 per cent were concerned about lack of friends and 46 per cent of the families had no suggestions for ways in which the services could be improved (Cheseldine and Jeffree, 1980). In accounting for these findings, it has to be borne in mind that these families had seen many improvements in services since their child was first born and were often appreciative of the extent to which services had changed for the better. It seems likely that the newer generation of parents of younger children may have higher expectations both of their handicapped children and of the services; in particular, those who have derived benefit from programmes of parent-professional collaboration while their child is at school are likely to press for further working contact with the staff of adult services (Mittler, 1979).

15. Policies of normalisation for the lives of handicapped people often originated with parent pressure groups. Yet, when it comes to change for their own child, parents may be afraid. With adolescents, parents fear their child being robbed, raped or getting lost. In one study, 40 per cent of severely mentally handicapped adolescents who had left school never went unescorted beyond the front gate (Stanfield, 1973). Parents may identify a lack of companions and proper recreational facilities as problems for handicapped adolescents, and yet tend to keep their own children in familiar company and not trust them out alone. Thus they may undermine the acquisition of skills identified as desirable for the young people by professionals. Ferrara (1979) found that parents of severely handicapped adolescents were more positive about normalisation policies in general than parents of the less severely handicapped. She noted that the degree of personal risk for these parents may be lessened because their children will require significant adaptations from "normal" patterns of living to suit their requirements. Boggs (1978) eloquently argues the problems for the severely handicapped: "Rather than trying to create a 'normal' environment for my son, I try to think of how the world must look from his point of view, and what kind of environment would not only minimise his boredom and loneliness, but enhance his sense of dominance." (p. 62)

16. Thus, parents of handicapped adolescents of all levels of ability may exhibit "negative parental attitudes" in the face of change. They may just want the best for their child, based on the limited information they have been given, or found out, about their child's abilities and possibilities. "They have seen the reality of what sometimes passes for community care, and no one may have explained to them how things could be otherwise." (Tyne, 1979).

17. School leaving is therefore a time when information provision and sensitive counselling are vital. Families who find themselves once again caring single-handed for their son or daughter are under considerable stress. The relatively structured existance imposed by the school day and the school year is replaced by one of uncertainty about the future, a situation which also makes considerable day-to-day demands on the family. It is often necessary for one member of the family (usually the mother) to give up a job in order to look after the handicapped person at home. The loss of income may be a further source of tension in the family as a whole. Furthermore, the less able youngsters may not fully understand why the regular routine of school has suddenly been disrupted or why they are having to spend so much of their enforced leisure at home. The more able young people are even more likely to resent lost opportunities for further education and training; some become bitter and disillusioned; others become unhappy or emotionally disturbed and may even show clinical signs of a depressive illness.

18. It is therefore ironic that many families are being deprived of services at the very time when they are most in need of them. They need opportunities to discuss their immediate and long-term needs with people who not only know their child but who are also well informed about local existing provision and services that are still being planned. They need to be helped to plan realistically for the future and to prepare the young person step by step to make the best use of whatever services are available. This may mean, for example, preparing him to live away from home, first for a day, then a weekend and then for progressively longer periods. Whether or not he leaves home, they will need continuing help to teach him to become more independent both inside and outside the family home. The extent to which the young person can live in the community will largely depend on the extent to which parents, or parents and professionals in partnership, have succeeded in teaching social independence and community living skills. This we see as one of the most important and distinctive roles of parents and families.

19. The extent to which the role of families can be realised will therefore depend on many factors which interact with one another in complex ways. The severity of the young person's impairments and disabilities, the opportunities that have been made available in earlier childhood to gain access to appropriate educational and treatment services, the attitudes and perceptions of the young person himself to these efforts - these all play an important part in affecting parents' attitudes to later programmes. Equally critical are the availability of appropriately staffed day or community services which are committed to active programmes of preparation for community living but which include relevant vocational training and further education, as well as help in using community recreational and leisure facilities. Without such services, families are necessarily thrown back on their own resources and are left

unsupported to cope with an adolescent who may be physically mature but who is in many respects still dependent on others and in need of skilled programmes designed to help him to take further steps towards social independence.

20. The following section summarises a number of recommendations that have been made for the kind of service provision which seems to be necessary to meet the needs of parents from the time when their son or daughter is approaching school leaving age.

III. The Service Needs of Parents

21. The time of school leaving provides an opportunity to take stock not only of the needs of the child but also those of the family. Families should feel that there is time and opportunity to discuss any aspect of their family life which concerns their child either now or in the future. Such discussions need not be limited to the immediate questions arising from school leaving and placement into adult services. Both parents and professionals are increasingly expressing the wish to move away from a crisis-orientated service towards one which anticipates needs and tries to plan constructively to meet them. For example, parents should be encouraged to discuss questions concerned with residential care long before there is a direct need for it.

Information

22. First and foremost, parents need information on the range of provision which is available or planned in their locality. In our own interviews with parents in areas where services were well developed, we found many parents badly informed about day or residential services for adolescents and adults. Very few had visited the Adult Training Centres which their children would almost certainly be attending in the coming months (Cheseldine and Jeffree, 1980). They were also poorly informed about facilities for short-term and longer-term residential care in their localities. Lack of information was more common among parents who were not members of parents societies or who did not receive the parent journals in which such issues are regularly discussed.

23. A number of authorities have been producing short information leaflets on local services. These generally contain addresses and telephone numbers of key organisations and individuals as well as useful information on where to get advice or help to meet particular needs. Unfortunately, these leaflets are often aimed at parents of younger children; there is a case for an information sheet written especially for parents of young people approaching school leaving age. This might include information on the following:

(i) local provision for assessment of young people approaching school leaving age - e.g. which professionals should be routinely involved in assessment and decision-making and which others are available for consultation if the need should arise?

(ii) procedures for parents to be involved in the process of assessment and decision-making; how and when they should be consulted; how they can obtain the information or advice which they feel to be necessary and whom to contact if they are dissatisfied;

(iii) the range of alternative provision which is available locally - e.g. day services, further education colleges, work experience courses, sheltered employment, vocational training. This should include the names of key individuals in these organisations who can advise parents and who might be able to arrange for preliminary visits to the agency;

(iv) the range of residential services - both long term and short term - should also be summarised in such a leaflet, together with some indication on how parents can visit such facilities informally;

(v) in addition to listing services for handicapped people, such leaflets should also include information on all relevant resources available to the rest of the community and to young people in particular - e.g. careers advice, work training, further education facilities, evening classes and the whole range of leisure, sport and recreational facilities in the area.

Anticipating needs for residential and support services

24. Such information leaflets may provide the basis for an informed discussion between parents and professionals on the availability of local resources. For example, parents often express the need not only to be told about the local services that are available or planned but also to have the opportunity to discuss the advantages of the various alternatives in relation to the needs of their son or daughter and of the family as a whole.

25. Discussion about the range of alternatives may also provide opportunities for families to express more general feelings about their attitudes and needs. To this end, it is obviously desirable that there are opportunities to relate to a single individual, preferably someone with experience of working with families. Such a person can provide the "single point of contact" recommended by the Warnock Committee in the United Kingdom (Department of Education and Science, 1978). Their role is not merely one of providing information and helping to ensure

that services are provided in a co-ordinated manner. It includes the more complex skills involved in helping families to express their anxieties and to discuss matters which are of deep concern to them. Families need time to get to know the visiting professional, to reassure themselves that he or she will come again, and is a person in whom they can have confidence. Only then will they trust themselves to express their deeper needs and feelings. For example, a quick and superficial visit to the family may well result in a report that the family are unwilling to consider residential care. But several visits and the development of a more open and trusting relationship may help the parents to speak more freely about their problems in continuing to provide 24 hour care and may make them less hesitant to express their wish to think about residential care outside the home.

26. Similarly, some parents may refer to arrangements that have been made for an older brother or sister to make a home for the handicapped youngster when the parents are no longer able to do so. This was mentioned quite frequently in our own studies, particularly as many of the leavers were the youngest of a large family, with many brothers and sisters now married (Cheseldine and Jeffree, 1980). In a separate survey, some 30 per cent of the children in special schools for the mentally handicapped came from families with four or more older children (Mittler and Preddy, 1980). But parents may be reluctant to rely on their other children to take over care, though there is evidence that older siblings no longer living at home tend to give considerable help and are willing to take over. Bayley (1973) found that among mentally handicapped adults living in the community, 85 per cent of those who could be living with a sibling (i.e. both parents dead) were doing so, though of those in hospital, half had been admitted immediately after the death of a parent. But such an arrangement is not necessarily entered into willingly by the older brother or sister or their spouse; it may be made in order to reassure worried parents that the handicapped youngster will be taken care of when the time comes. Furthermore, circumstances can change, particularly in a growing family. For these and other reasons, it is important for the professional not simply to record that family arrangements have been made but to explore the situation in some depth and detail with the parents and the younger family involved.

27. In our interviews in the Greater Manchester area, we found few families of school leavers who were well informed about the residential services which were available in their area. Many still assumed that the long-stay mental handicap hospital was the only alternative to remaining at home and were unaware of existing and planned local authority provision for hostels and group homes. The movement towards the use of ordinary housing for handicapped people, although increasingly influential in professional circles, has not made the same impact on individual families.

28. It has been our experience that parents expect to continue to provide a home for their handicapped son or daughter indefinitely, until they are no longer able to do so by reason of age, incapacity or death. The notion that young people might be given opportunities to live away from their families before there is a crisis has as yet made relatively little headway. This is partly due to the shortage of provision in the community but is also related to the narrow range of alternative accommodation which has until recently been considered appropriate. This may change, now that more consideration is being given to the use of ordinary housing and evidence is beginning to be published indicating that even severely handicapped people can live in ordinary houses. The amount and nature of the support they will need will obviously vary from person to person. In the field of mental handicap, the scheme developed by the Eastern Nebraska Community Organisation for the Retarded (ENCOR) for a wide range of living units in the community is beginning to become influential in the United Kingdom and in other European countries (e.g. Thomas, Firth and Kendall, 1978; Mittler, 1979a). Furthermore, some advisers are now cautioning against the adoption of over-simplified notions of placement - e.g. that people with certain levels of disability need one form of care whereas those with lesser degrees of disabilities need another (Development Team, 1980). Instead, current thinking emphasizes the possibility of developing small homes for groups who are not necessarily homogeneous in terms of severity of handicap, though such a policy is clearly not without problems. Nevertheless, it seems useful to counter the prevalent assumption that some people are inevitably "hospital" cases, while others are "hostel" or "group home" cases. Such predictions are likely to be self-fulfilling, and need to be questioned by professionals and parents alike.

29. The notion that each community should provide homes in the locality for all its handicapped citizens is only now beginning to be seriously discussed. Professionals have come to accept that the number of handicapped people who actually require specialised long-term residential services in hospitals or other institutions is very small; furthermore, studies of such institutions have shown that their resources are often so limited that such specialist needs are rarely adequately met (e.g. Oswin, 1978; Development Team for the Mentally Handicapped, 1980). In the United Kingdom at least, well over four-fifths of severely mentally handicapped children and about a half of the adults are living in ordinary houses with their families; such houses may require a range of adaptations to meet the needs of people with severe physical handicaps but many countries are now developing legislative and financial provision for this purpose.

30. Providing ordinary or adapted housing in the local community means that people can live in small units with as much staffing and support as their individual needs require. Some will require only a very occasional visit from a social worker,

health visitor or voluntary worker; other houses may contain three to five more dependent people who will need to have staff living in the house with them; in other cases, professional staff live in a nearby house but are available when needed. The emphasis in such schemes is on providing a wide range of residential accommodation to meet the wide range of need of individuals.

31. From the parents' point of view, such arrangements provide ideal opportunities to help their sons and daughters to learn to live more independently. At the same time they can prepare themselves to accept that although they will eventually need to live away from home, such a home need not be a distant hospital or institution but a house not very far away from their own.

32. Quite apart from questions concerned with long-term residential care, families also need opportunities to discuss questions concerned with short-term care in their area. Although hospitals have traditionally made the major contribution to short-term care in Britain, particularly during the summer holidays or in emergencies, local authorities and voluntary organisations have also begun to make provision (see National Development Group, 1977 for a summary of suggestions on how short-term care might be organised at local level). Here again, families may be unaware of these developments and still assume that short-term care is available in hospital or not at all.

33. Many families will need some short-term relief from the strain of coping. Play schemes during school holidays, and occasional care at the weekends are seen as the most strongly felt needs of parents of younger children (e.g. Barnado's, 1979). Wilkin (1979) makes the point that it may be important to ask what a family would "like", because he found that mothers were not inclined to identify "need" if they were actually coping. In his study of severely handicapped children at home, 68 per cent of families felt the need of minding in the school holidays (48 per cent said it was "very important"), 48 per cent felt the need for some day care at weekends, 40 per cent for help with "baby sitting" in the evenings and 51 per cent needed help with transport (p. 192). However, Lonsdale (1978) reported that 45 per cent of the parents she interviewed considered short-term hostel care unnecessary and would never place a child of theirs in one. They relied in emergency on the family circle and would not "put the child away", though this attitude may be related to the age of the child, Lonsdale's sample being only up to 12 years of age. Some parents seem to fear the loss of a companion, if the young person is more independent. It is often reported that young handicapped people lack friends and contacts outside the family; this isolation may have affected the whole family as well as the handicapped member (Holt, 1958; Boruchow and Espenshade, 1976).

Financial Help

34. Many countries are now introducing a range of financial grants and allowances both to families and to the handicapped person. The whole question of disability allowances is generally extremely complex and difficult to understand and parents will almost always need to have access to sources of expert advice. Some cities in the United Kingdom have therefore appointed a welfare officer specifically for disabled persons and their families. This person is independent of the authorities and seeks to ensure that all families obtain the full range of benefits to which they are entitled. Even where such an appointment is not made, clearly written information leaflets are obviously needed, together with suggestions on how further information can be obtained at local level. Here again, these questions need full discussion between parents and professionals.

35. Information and opportunities for full and informal discussion between parents and professionals constitute essential foundations for any locally based service. But recent thinking also emphasizes that much can be achieved by the development of a more active working partnership between parents and professionals in helping the young person to learn to live more independently in the community. The following section examines the nature of such a partnership in greater detail and outlines some of the obstacles to its achievement.

IV. Partnership Between Parents and Professionals

36. Partnership with parents is now seen as the hallmark of a good service for handicapped children. Starting at the time when the handicap is first identified, continuing through preschool and into the period of formal schooling, partnership between parents and professionals is seen as making a major contribution to meeting the needs of children, parents and professionals alike. The available evidence suggests that handicapped children will respond more favourably to teaching and developmental programmes if parents and professionals are working together than if either is working in isolation (Cunningham, 1975). This is true not only of handicapped children but applies also to those who are "socially disadvantaged". The nature of the partnership will vary from family to family and will depend on the needs of the child but a number of elements can be distinguished:

(i) Involvement of parents in the comprehensive assessment of the child's abilities and disabilities, strengths and needs. Clearly, the parents' knowledge of what their child can and cannot do is invaluable to the teacher. This is particularly true of the more severely handicapped children for whom parents and teachers will share similar goals - e.g. in teaching self-care and social independence skills.

(ii) Arising directly from joint assessment, teachers and parents can benefit greatly by collaborating in drawing up long-term and short-term goals and in discussing how they are going to work together to help the young person to reach those goals.

37. The kind of collaboration which we envisage between parents and professionals ideally calls for a home visiting or domiciliary service. This is not intended to replace visits to the school or agency by parents but rather to complement it. A home visiting service is even more essential where the handicapped person is not regularly attending any form of day service; in such cases the main responsibility for helping parents to provide teaching and other forms of training falls on the home visitor.

38. Examples of such a home visiting service for parents of pre-school children can be found in the Portage programme developed initially in rural areas in the United States but now successfully replicated in the Caribbean and in parts of Europe (Shearer and Shearer, 1972; Revill and Blundem, 1978, 1980). The model here is one in which a home visitor visits families about once a week in order to work with the parent to select short-term goals and to introduce specific structured methods which the parent can use to try to teach the child to reach such goals before the next visit. Although the teaching targets would require considerable modification for adolescents and their families, the model of a home visiting service in which agreed goals are taught could well be found useful by parents and professionals. It might, for example, be used by peripatetic instructors based on Adult Training Centres, as suggested by staff themselves in a national survey (Whelan and Speake, 1977).

39. Even where the young person is not in regular contact with professionals, parents can be given the means to try to develop active teaching methods which are designed to help the young person learn new skills and to become more independent. Our colleagues Edward Whelan and Barbara Speake have written a teaching manual specifically for parents of mentally handicapped adolescents (Whelan and Speake, 1979). Beginning with a "Scale for Assessing Coping Skills", parents are helped to complete a simple check list of the young person's abilities in the areas of self-help (personal, domestic, community) and interpersonal (e.g. conversation, friendship, sexual knowledge and behaviour). Detailed suggestions are then made for ways in which parents can design and carry out a teaching programme to help the young person achieve specific skills. Such an approach can also form the basis of structured workshops in which groups of parents and professionals meet regularly in order to define short-term goals and agree on methods of reaching them.

40. But although professionals and parents of handicapped children have worked in closer partnership during the past ten years there are few reports of similar parental involvement in services for handicapped adolescents and young adults. Are there distinctive problems about developing such a working relationship between parents of adolescents and adults and the staff who work with them?

41. Parents frequently complain that they are not involved in the process of decision making about their son or daughter. For example, when there are case conferences to discuss future placement after leaving school, parents may be left to wait outside while the discussion is proceeding among professionals and are only invited in to comment on a decision that has already been formulated. This is less likely to happen if parents and teachers have worked together during the school years in developing joint assessments of the child's abilities and in collaborating on programmes of teaching. But parents of the oldest children in a school may not be as familiar with such an approach since this has often only been developed in recent years and with parents of younger children. They may therefore need more encouragement to involve themselves in discussion and decision making about the future.

42. Because parents and professionals may not have the same goals, it is important to provide opportunities for a free discussion to identify expectations of the level of independence that may be achieved, since these may differ widely in both groups. Just as several professionals working with the same adolescent may have different expectations of the final outcome, so different members of the same family may vary considerably in their estimate of the extent to which the young person can learn the skills to live successfully in the community. It may therefore be helpful to explore these questions through discussion. It is clearly dangerous to press ahead with carefully structured training programmes to teach social independence when one or both parents may have misgivings about whether such a programme is justified. They may also be anxious about the risks involved in undertaking it. Questions concerned with sexuality represent the most obvious examples where full discussion about goals and philosophies is important. Similarly, parents and professionals may have different perceptions about the extent to which a particular youngster is "ready" to start a course of social independence training - e.g. in learning to use public transport, go to a supermarket or a disco unaccompanied, to go on holiday with a group of friends, etc.

43. Even where parents and professionals are apparently agreed on the overall programmes for social independence training, difficult issues arise when it comes to discussing the nature and degree of parental participation in such programmes. Although there is now a strong body of evidence which testifies to the effectiveness of intensive parental involvement where teaching programmes with younger children are concerned, is it right to extrapolate these to parents of adolescents and young

adults? Even if direct parental involvement in social independence programmes is likely to be beneficial to the adolescent, how appropriate is such detailed involvement from a "normalisation" point of view? Is it appropriate that parents should know exactly what their son or daughter is doing in the course of their day to day social education or training programmes? Even very much younger children like to maintain separate identities between home and school and tend to fend off well meaning enquiries from parents about what they have been doing in school. It could be argued that even where such enquiries are not apparently resented and even where parents and professionals are working well together to achieve goals that are in the long-term interest of the adolescent, such a close involvement on the part of parents may in fact reinforce rather than diminish dependency.

44. These issues about goals and philosophies are not widely discussed in the literature, nor, we suspect, do they receive as much consideration as they should at the level of the individual family when professionals are beginning to draw up training programmes for handicapped young people. Professionals may themselves need help in facing these issues; for example, group discussion, possibly accompanied by role play may help staff to face some of the delicate and complex issues involved. Clearly, no two families have the same needs but certain general strategies can be discussed within a group. For example, some parental involvement programmes may begin with a fairly intensive and detailed level of training by parents but in the context of a clearly worked out plan to reduce the amount of parental involvement on a step-by-step basis. This can be done more easily with some programmes than others - e.g. in teaching a young person to travel to a day centre by public transport, the programme would probably consist of gradually "distancing" the parent from the young person. Similarly, the amount and intensity of supervision in teaching a young person to wash their hair can also be slowly but systematically withdrawn.

45. Now that parents are being asked to enter into detailed and often day-to-day working partnerships with professional staff in teaching their son or daughter to acquire specific skills, it is particularly important to provide opportunities for them to express their feelings about any difficulties they may be experiencing in working in a teaching role. Some parents quite understandably find such work both demanding and stressful but may find it hard to admit to this, for fear of being thought unco-operative or not "good parents". They need to be encouraged to be quite open about these matters; parents should not feel forced to undertake demanding programmes of day-to-day work and should be able to express their feelings about these matters, preferably to someone who is seen as helpful and in whom they can feel confidence.

Obstacles to parent-professional collaboration

46. Although collaboration between parents and professionals has made considerable gains during the past ten years or so, it is as well to recognise the serious obstacles which stand in the way of further progress in this direction. We will briefly list some of these, distinguishing between those primarily relevant to professionals or to parents. We also refer to some recommendations which have been made to try to increase collaboration. These are based on an invited paper prepared by one of us for a UNESCO meeting on special education (Mittler, 1979b).

Professionals

(i) Lack of discussion and preparation for parental participation in their basic training.

(ii) Resistance and anxiety at the prospect of parental involvement in schools and programmes. Problems incoming to terms with parents as partners.

(iii) A tendency to display their expertise and to adopt a didactic and sometimes authoritarian approach to parents.

(iv) Difficulty in sharing their own limitation in knowledge and skill with parents.

(v) Tendency to make excessive demands on parents - e.g. in the form of teaching sessions, record keeping, attending meetings.

(vi) Failure to take account of the variety of needs and the range of variation from one family to another.

Parents

(i) Difficulty in coping with the demands now being made of them by professionals; they may be too busy, too exhausted or too pre-occupied with day-to-day problems presented by the handicapped person or by problems concerned with poverty, poor housing, unemployment or chronic ill health.

(ii) Problems in reconciling demands made by the handicapped person with the needs of other members of the family - marriage partner, siblings, grandparents.

(iii) Tendency to attribute too much expertise to professionals - e.g. resulting in the assumption that staff will accept full responsibility for training a young person in, say, social and domestic skills.

(iv) Under-estimation of the abilities and potential of their child to respond to independence training, possibly due to a history of earlier failure.

(v) Where parents do succeed in collaborating with professionals in achieving goals for the handicapped person, they may tend to undermine "professional expertise" by displaying competence in the use of techniques and terminology traditionally regarded as the exclusive preserve of professionals.

Suggestions for increasing collaboration

1. All programmes of initial training for teachers and other professional personnel should review the extent to which questions concerned with parental involvement are incorporated into the curriculum.

2. Special courses concerned with this subject should be mounted at the in-service and post-experience level. These should review existing information on this subject and provide opportunities for discussion and experiment with a range of approaches to parental involvement in local services.

3. Persons with advisory or administrative responsibilities for special education should review the quantity and quality of parental involvement programmes in their own areas and, in doing so, consult with local parents and parent associations.

4. A selective bibliography on parent involvement including reports of successful programmes should be prepared in each country and made available to all headteachers, advisers and programme directors.

5. Programmes of research and development on parental involvement should be encouraged in each country.

6. Appropriate parent organisations at national levels should be invited to submit their views on parental involvement in school and other service programmes and to put forward suggestions for new developments in this area.

V. Needs and Rights of Handicapped Adolescents

47. Up to this point we have considered the needs of parents and examined aspects of parent-professional collaboration. In the following section we will outline the rights and needs of the handicapped adolescents themselves. We cannot assume that handicapped adolescents necessarily have the same rights as their peers, nor that their interests and needs necessarily coincide with those of their families.

48. There have been a number of official statements in recent years concerning the rights of disabled persons. Because these are usually couched in general and somewhat idealistic terms, it seems important to consider concrete and highly specific

questions which will identify the extent to which any given right is actually reflected in the availability of local services. For example, the U.N. Declaration of Rights of the Mentally Handicapped (1971) has been "translated" into a large number of specific questions by the International League of Societies for the Mentally Handicapped (Step by Step, 1978) so that groups of parents at local level can identify the extent to which general statements of rights are reflected in service provision in their own locality. Similarly, the English parents society (Mencap) have produced a series of "minimum standards" documents (STAMINA) for schools, Adult Training Centres and residential extablishments and is preparing others in the area of employment and leisure services. We also wish to refer to the "Charter for the 80's" which is being promulgated by Rehabilitation International in connection with the 1981 International Year for Disabled Persons.

49. For the purpose of the present discussion, we will summarise the Declaration of Rights of Disabled Persons promulgated by the United Nations in 1975.

United Nations Declaration of Rights of Disabled Persons (1975)

(i) The same civil and political rights as other human beings

50. In many countries special legislation has been implemented to protect the rights of the mentally handicapped. For example, in the United States litigation brought on the behalf of mentally disabled individuals has sparked what is often referred to as a revolutionary "patients' rights movement". Judicial decisions affirming these efforts have been incorporated into state laws and have led to federal legislation such as the Rehabilitation Act, and the Developmentally Disabled Bill of Rights and Assistance Act. These federal statutes and their regulations define important new rights for mentally disabled persons and create major new challenges for legal advocates.

51. For the parents there is the question of whether they are permitted to know what records are kept on their son or daughter and whether they have access to them. When the young person comes of age, does he/she have this same access, and indeed, should parents still have the same rights at this point?

52. However, some restrictions remain. In the United Kingdom, mentally handicapped persons may be refused the right to vote in an election, although properly registered, if the returning officer thinks they seem unable to do so properly. For those who are permanently living in hospital there may be problems in becoming registered to vote, although this is now being challenged in many cases.

(ii) Help to become as self-reliant as possible

53. It seems quite logical that the transition from adolescence to adulthood should be a time for the young person to become more independent - socially, emotionally and financially. It is a time when parents of most young people are encouraging behaviours which gradually fade out the support of the family and home so that the adolescent becomes a viable member of the community.

54. How far does this happen for the more severely handicapped? Is there not a tendency to extend and prolong the effects of the disability by keeping the young person in a "cotton wool" environment? We should not be too quick to criticize parents for being "overprotective", but should also examine the ways in which professionals are guilty of this, e.g. by providing special transport to special schools and day centres so that the young person never has the opportunity to learn to use public transport, or to mix with non-handicapped peers.

55. We must also consider just whose "rights" are involved in such issues. It has been suggested, (Ferrara, 1979) that parental aims and aspirations may be inconsistent with those of professionals. What if the school or training centre wish to encourage independence, e.g. through the use of public transport, but the parents disagree?

56. It generally seems, in England at least, that where parents do not agree with programmes suggested by the school, that their wishes are respected. But the possibility of the adolescent having a differing opinion from that of his parents, teachers or employers is seldom raised, as it is assumed that the severely mentally handicapped will merely acquiesce, or accept any decisions taken.

(iii) Proper medical care and treatment

57. Improved training of medical and para-medical staff is gradually ensuring the provision of specialised treatment and techniques for the mentally handicapped. In England and Wales a young person aged 16 years or over is normally deemed competent to consent to surgical/medical treatment. However, in many circumstances the severely mentally handicapped are deemed "not competent", even if aged over 16 years. Their wishes may be overidden by reference to guardianship if thought appropriate (Mental Health Act, 1959). When officially an adult at 18 years, the young person may be deemed just as "incapable", and at this point the parents can, strictly speaking, only make these decisions if they are made guardians. However, in practice, these problems are seldom brought to light. A social worker or the patients' nearest relative can apply to be a guardian, on the grounds that the "patient" is under 21 and subnormal, or any age and severely subnormal(as defined in the Act). However, the social worker cannot apply if the parents object, and would instead apply to the County Court to "replace" the relative because of unreasonable objections.

58. Handicapped adolescents should also have the same right of access to specialist services such as speech therapy and sensory aids as their non-handicapped peer and should not be excluded on the grounds that they are "too handicapped" to benefit from such treatment.

(iv) Education, training and rehabilitation, and guidance

59. While basic primary and secondary education is now normally available to all handicapped children, leaving school may represent a time of uncertainty, with no guarantee of a place in a training centre, and limited opportunities for tertiary education. Yet many of these young people may show an intellectual spurt at around 15-16 years (Swann and Mittler, 1976) and it therefore seems illogical to stop education at this point. Not only is greater provision needed, but the adolescents and their parents need to be aware of the facilities available (UNESCO, 1979).

60. It is essential for the young person to have a balanced assessment prior to leaving school, with a full case conference involving the parents and the adolescent in the decision making. In an alarmingly high percentage of instances there is no case conference at all (Fleming, 1978).

(v) A decent level of living, including the right, according to individual abilities to secure and retain employment

61. In the current age of strong trade unions, it may seem remarkable that so many receive such small payment for a fair day's work. While it might be necessary to review the system of benefits and allowances that are in operation, and which affect the amount that can be earned, it is also essential to realise that a reasonable income is vital if one is to be independent - not only for essential purchases, but also for the enjoyment of recreational amenities in the community. This raises a difficult topic as to whether the young person can regard his earnings as his own, or whether they are handed over intact to his parents. Apart from the ethical issue, there is the problem of lost opportunities to learn to handle money. Cheseldine and Jeffree (1980) found that 76 per cent of a group of 214 mentally handicapped adolescents were unable to proffer a reasonably appropriate amount of money for small purchases. The proportion remains as high as a half even for adults attending Adult Training Centres in England and Wales (Whelan and Speake, 1977).

62. There is a tendency to talk of "placing" mentally handicapped teenagers in jobs, rather than them "getting" a job. Seldom do these young people have the chance to find out about various types of employment, and to make a choice, although there is evidence demonstrating their ability to do so (Reiter, 1975). In some cases the mentally handicapped may be "found" jobs in a family concern although they could be quite capable

of finding their own. While this guarantees employment, it nevertheless may restrict contacts and opportunities for integration in the community. Where work is open, or even sheltered employment is obtained, prospective employers and fellow workers may need some preparation and guidance. Support for the young person may take the form of advocacy, such as that in the United States, and that sponsored by the NSMHC Pathway Scheme in the United Kingdom, where fellow workers are recruited to act as foster workers for the mentally handicapped worker, and "show him the ropes" in a new job (Cooper, 1978).

(vi) A normal living environment, within a family where possible, including participation in all social, creative or recreational activities

63. For the young person suddenly removed from a stimulating school environment and left at home, this may prove a particularly frustrating experience. The mentally handicapped adolescent has as much right to make the most of his spare time as any other young person.

64. One obvious solution to this problem is to ensure that recreation and leisure skills are taught and included in the school curriculum. Leisure is an essential part of rehabilitative programming, and an ideal medium for integration, and yet it is often neglected. While a great deal of time and effort has been spent on training work skills, this has not been done for recreation, possibly because of the wide continuum along which such skills would fall.

65. Research carried out at HARC (Jeffree and Cheseldine, 1980) has shown that while the young people may be aware that various activities exist (such as football, cycling, etc.) they actually participated in very few. The most frequently reported activities were solitary, passive ones such as watching television and playing records. There were a number of reasons for this. The teenagers often lack the social skills necessary to do more, e.g. ability to get out and about the local community, use of money. They seldom have any friends living nearby to share these pastimes with, mainly due to the large catchment areas of special schools. They may not have had any experience in any other sort of activities. There is an obvious role for the parents here in extending the activities and social contacts available to the young person. But in addition to parents being older and less active themselves, they may well see no "problem" as such with regard to leisure activities.

66. Special youth clubs (e.g. Gateway Clubs in the United Kingdom) are available in many areas, but these do not suit all needs. Many teenagers have "dropped out" because they do not want to mix with their handicapped peers out of school as well as in.

67. These clubs pose another question, viz. to what extent should parents be encouraged to take part in these leisure activities? Would it be "normal" for parents to come along to the club, as they often do? Do they inhibit the young people? Schalock and Harper (1979) indeed suggest that parents are a reason for adolescents not doing more in their leisure time. In an attempt to fade out their support, this might be a suitable stage to introduce volunteer non-handicapped young adults to accompany the disabled adolescent on various excursions and activities.

(vii) Protection from exploitation, discrimination, abuse or degrading treatment

68. Inevitably protection from exploitation has meant the introduction of legislation, e.g. so that the mentally handicapped might not be drawn unwittingly into binding contracts. However, this also imposes restrictions, in the the disabled persons are prevented from buying goods by hire purchase even though they may be earning a good wage - a right that is not denied their non-handicapped peers.

69. Restrictions are also imposed on the severely mentally handicapped with regard to house ownership, even if the property is inherited, and also with the owing of large sums of money. In both cases trustees would have to be appointed to administer estates and this may present a sizeable problem to parents who wish to provide for their son or daughter after their death. Efforts are being made to overcome this problem by various organisations (e.g. Mencap in the United Kingdom) who are willing to administer properties as groups of homes for the mentally handicapped, but accepting provisos made by parents such as limitations on the number of occupants.

70. To ensure that adolescents and parents receive the maximum benefit from services and are fully aware of their rights, there will be a need for skilled counselling. Counselling for the adolescents themselves, as distinct from counselling for their parents, is also important at this stage. Not only are they having to come to terms with the physical and emotional changes occurring in adolescence, and trying to acquire status among adults and their peers, but they are also having to come to terms with their handicap and the restrictions this will impose on them, and having to learn to make choices when faced with an increasingly diverse range of options, e.g. for leisure or work. It would seem essential that the adolescent should be able to have his own counsellor with whom he can talk things over. Indeed in the United States, moves have been made towards introducing group counselling for mentally handicapped teenagers (Hulmes et al., 1969; Zisfein and Rosen, 1973; 1974).

71. This support would be most useful in helping the mentally handicapped young person to become more assertive, in standing up to being treated as a "second-class citizen". Parents are not to be excluded at this point, however, as they have a vital role to play in introducing the young person to new experiences, to provide opportunities for making choices and for being non-acquiescent.

72. Zisfein and Rosen (1973-1974) introduced a programme aimed at improving levels of self-regard, reducing acquiescent or submissive behaviour, and patterns of helplessness, and encouraging the learning of self-initiated problem-solving behaviour and appropriate heterosexual responses. For many young people the development of socially appropriate behaviours may be largely neglected, and as such tend to be seen under the overall heading "sexual behaviour". However, the most basic skills need to be dealt with first, such as physical proximity, acceptable touching behaviours and other aspects of social communication. Parents again can play an important role in this aspect of development, but both they and the young people may need specific counselling at this stage.

73. Techniques of role-play, modelling and the use of video-recording, such as those used at the Vocational Rehabilitation and Research Institute in Calgary, Canada, are being used to teach socially appropriate behaviours, to enable the mentally handicapped to stand up for themselves in situations which may otherwise produce results to their disadvantage (Ryba and Brown, 1979).

74. We have not attempted to provide anything like a comprehensive list of the services which will be needed by handicapped adolescents or their families; these will vary from country to country and from community to community, depending on local circumstances and the kind of resources that can be mobilised. But in considering the kind of services that might be provided, it nevertheless seems useful to base these on statements of the rights of handicapped persons, whether promulgated at international or national levels, even though these will need to be modified in the light of local circumstances and individual need. The fundamental philosophy underlying most of these principles is concerned with the rights of the handicapped person to have access to all the resources and families of the community and to live in as normal an environment as possible. This in turn calls for full participation and integration into the life of local communities and the avoidance of separate and segregated facilities. At the same time, we must recognise that some handicapped people need active, systematic and structured help to enable them to live and work in the community. Merely placing them in the community in the name of integration is not enough.

VI. Conclusions

75. We have argued that the role of parents of handicapped adolescents is not fundamentally different from that of any other family namely - to provide a loving and secure home and to prepare them to live as independently as possible in the community. But parents face many difficulties in carrying out this role and are seldom given adequate support or practical help at what is often a difficult time. The needs of each family will obviously differ greatly depending on the problems presented by the adolescent and the parents' perception of how far the ultimate goal of independent living in the community is a realistic one.

76. These and many other issues need discussion at some depth between parents and professional staff who may have different perceptions of the present abilities of the adolescent and the extent to which he or she can become more competent and independent. We have argued for the development of a close working partnership between parents and professionals, similar in some respects to that being developed with parents of younger children but differing to the extent that the young person is or will soon be legally adult, with the rights and responsibilities that go with adult status. If the goal of training and rehabilitation is the maximum degree of independence, equal partnership between parents and professionals will be needed to define goals and how they can be reached. For example, it is often necessary to develop detailed step-by-step programmes to help the young person to become more socially mobile, by using public transport and going to places of entertainment. This may arouse a considerable degree of anxiety if the parents feel that the young person is not yet ready for this kind of training and that harm may be done by pressing too hard and too early. On the other hand, it may also happen that professionals are criticised by parents for setting too low a standard and for not developing a regime of demand and expectation.

77. Partnership between parents and professionals can take many forms, but certain elements can be clearly distinguished at the time of school leaving. Parents should be fully involved in the process of assessment of strengths and needs and should be seen as full members of the multi-disciplinary team, participating in detail in contributing their unique knowledge of their child's abilities and needs and in making decisions on how these can most appropriately be met locally. To this end, parents will need to have full information on local facilities already available or planned. Following this, parents and professionals can try to work together to plan and implement a programme which aims to help the young person to learn new skills, and to become more independent, and to use an increasing range of community resources and facilities. But parents also need to be able to express any doubts they may have about the ability of the young person to learn to live more independently and to discuss any anxieties they may have about the future, particularly where questions of alternative systems of residential care are concerned

78. But the most important contribution has to come from the handicapped adolescents themselves. Although parents and professionals may work well together and be agreed about short-term and long-term goals and methods of achieving them, it is essential to involve the young people themselves to the greatest possible extent by encouraging them to express their own views and by giving them as much information as possible on which to make informed choice. Parents and professionals may, singly or in combination, assume that they "know what is best" or that the young people are not in a position to express their own views. But even severely handicapped adolescents have shown themselves capable of expressing choice and an informed opinion and made it quite clear that they have a right to be consulted. Some mentally handicapped people have organised their own conferences or attended professional conferences in order to talk about their experience of the services being provided and their wishes for more opportunities to contribute to decisions which will affect their everyday lives.

79. People living in residential care have begun to insist on a greater degree of participation and are increasingly objecting to the lack of consultation in the running of both day and residential services. When their opinions are sought, it often becomes apparent that they do not by any means agree with the goals which either professionals or parents themselves have set for their future.

80. Where the aims of parents and professionals do coincide with those of the young people, the resulting programme is likely to be all the more successful and satisfying.

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